NOVA SCOTIA AIDS STRATEGY

DRAFT

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Nova Scotia Advisory Commission on AIDS

EXECUTIVE SUMMARY

The Acquired Immune Deficiency Syndrome (AIDS), identified ten years ago, has challenged the ability of societies, governments and individuals to respond to a variety of social, legal, and medical issues. AIDS is not a single disease, nor does it affect a single group of people. AIDS is the final stage of HIV Disease, which begins with HIV infection and usually ends in death due to an opportunistic infection.

Although the province of Nova Scotia has reacted very well to some aspects of this disease and its consequences, there is no reason for complacency. Changes in the populations most susceptible to new infection require that the Provincial Government adopt a strategic approach to dealing with AIDS in the future. Representatives of government departments, AIDS Service Organizations and the Nova Scotia Advisory Commission on AIDS have cooperated to develop the strategy outlined in this document. Implementation of the strategy will depend on partnerships between the government and community based AIDS organizations.

The populations affected by HIV Disease have changed during the past decade, as have the behaviours which encouraged transmission of the HIV. The elements of the strategy recognize the importance of maintaining many existing programs while developing an integrated preventive medicine approach to achieve new initiatives which will ensure achievement of the strategic goals of: **eradication of HIV Disease**; and **maintaining existing levels of care, treatment and support for those affected by HIV Disease.**

Both immediate and long term objectives leading to the strategic goals have been established. They are classified using a three level system, based on the balance of three factors:

1. Perceived Need;
2. Existing Resources; and
3. Potential Benefits.

Designation of level reflects the importance of emerging issues but does not mean that existing efforts can therefore be reduced. Level three objectives, in most cases, require **ongoing provision of resources**, whereas level one objectives require **immediate commitment of fiscal and human resources to allow for action.**

Strategic objectives are organized in the following fashion:

Education and Prevention

Targeted programming is critical to eliminating infection with HIV because it enables people to understand the nature of the disease and, more importantly, change their behaviours.

Level one target audiences are: men who have sex with men; illicit injection drug users; youth ages 13 through 18 who do not receive AIDS education in an institutional setting; and youth attending provincial high schools.

Level two objectives include targeted programming for: sexual partners of individuals at risk; and education and policy development for provincial workplaces.

Level three objectives are: targeted programming for populations increasingly affected by HIV; persons living with AIDS and their caregivers, and incarcerated populations; coordinated education and prevention programs; and maintaining and increasing public awareness.

Protection, Care, Treatment and Support

Nova Scotia has provided high quality care and treatment of individuals with HIV Disease. The Province has had less success in supporting those affected by HIV Disease and it has not been successful in building trust within affected populations.

Level one objectives are: changes to the Health Act to permit non-nominal reporting of positive test results; and building trust in affected populations.

Level two objectives are: promoting awareness regarding recent changes in the Human Rights Act and the ability of the Human Rights Commission to respond to requests for assistance given the greater breadth of its responsibility; ongoing consideration of anonymous HIV testing and counselling; ongoing education of health professionals; and financial support for AIDS service organizations.

Level three objectives include: access to and availability of treatment and care of those HIV infected; and the availability of social services.

Research

Objectives related to research have all been assigned to level three because Nova Scotian researchers have historically cooperated with others in their field both nationally and internationally, and because medical research is generally a federal responsibility. However, there may be specific areas in which research on HIV Disease in Nova Scotia would provide information not available from other sources. Research objectives include: examination of social-behavioral patterns; epidemiology; economic and legal ramifications ; and encouragement of cooperative biomedical research.

Coordination of Effort

The primary responses of the Government of Nova Scotia to the challenge of HIV Disease have been education in provincial educational institutions, and the provision of health care. The primary response of community groups has been to provide education to the general public, counselling and financial support to those affected by HIV Disease, and educational support to provincial institutions.

In some cases government departments have not coordinated their efforts. In many cases government and community groups have not communicated, much less coordinated their efforts. This has led to inconsistent access to services for persons with HIV Disease and some duplication of educational programs.

It is important that both the government and community groups understand and appreciate the role which each is best equipped to play. In addition, interdepartmental coordination of effort is necessary to ensure that human and fiscal resources committed to AIDS are most efficiently used at both government and community levels.

Implementation

Implementation of the Provincial Strategy should be facilitated by an interdepartmental committee made up of individuals from each government department who have responsibility for AIDS related programming within their agency. The committee would meet twice each year and at other times as required, and be chaired by the chairperson of the Nova Scotia Advisory Commission on AIDS. The Commission would act as the secretariat to the committee and would provide annual reports of its activities to the government.

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INTRODUCTION

The Acquired Immune Deficiency Syndrome (AIDS) was first identified in 1981. To the best of our knowledge, this syndrome is caused by the human immunodeficiency virus (HIV), which is passed from individual to individual by the exchange of bodily fluids. These fluids may be exchanged through unprotected sexual intercourse or activities that allow for direct blood to blood contact; the main example of the latter is the sharing of contaminated needles.

The World Health Organization estimates that worldwide there currently are 8-10 million adults and 1 million children infected with HIV. In terms of cases of AIDS, the World Health Organization reports a cumulative global total of 384 000 cases, Canada reports 5349 cases meeting the surveillance case definition for AIDS, and in Nova Scotia, 81 cases of AIDS had been diagnosed, all as of October 1991.

HIV Disease is represented by a spectrum beginning with infection by the HIV, which may remain dormant for up to 10 years within an individual's system, however the presence of the HIV can be detected within approximately 6 months of infection. The disease manifests itself at some point ranging between 6 months and 10 years by means of opportunistic infections such as unusual forms of pneumonia, fungal infections, and/or cancer, all of which are difficult to treat in the absence of a properly functioning immune system. A small number of drugs are available, which appear to significantly retard the replication of the virus, allowing many infected individuals a much longer period of time prior to the onset of full-blown AIDS. It is unknown how many residents of the province now have HIV Disease, however, approximately 120 individuals are treated at the Victoria General Hospital HIV Clinic on a regular basis.

On a world-wide basis, HIV Disease has affected all segments of society, with the vast majority of cases having been caused by transmission of the virus through unprotected sexual intercourse. In North America and Western Europe, the populations most affected to date have been men who have sex with men, while in several African countries, the disease has been equally prevalent in females and males engaged in heterosexual activity. More recently, in the United States, prevalence of the disease has rapidly increased among individuals who share needles during the use of illicit injection drugs.

HIV Disease has challenged the ability of society to treat everyone with equality, sensitivity and compassion. In many areas, the groups most affected by HIV Disease, are members of visible or invisible minorities such as, homosexual men, illicit injection drug users, and the poor, minorities which are already considered on the fringes of society. This has often resulted in discrimination in care, treatment, and support which is supposedly based on HIV status but which actually reflects the historic social marginalization of these groups. The presence of HIV has forced governments and individuals to examine their own unknown prejudices and fears. Increasingly, society has responded by providing social rights, social benefits and medical assistance in a more equitable manner.

The Nova Scotia Response

Nova Scotia has responded positively to the HIV/AIDS epidemic in many ways. The Provincial Government has already adopted necessary measures to provide medical care and treatment to people with HIV/AIDS and has committed resources to new initiatives in research, and education and prevention.

What has been lacking, however, are effective long term strategies for preventing new infections, for effecting behavioral and social change, and coordinating programs.

The Nova Scotia Task Force on AIDS

In 1987 the government of Nova Scotia initiated its Task Force on AIDS which submitted its final report to the Minister of Health in September 1988. As a result of recommendations contained in that report, an Advisory Commission on AIDS was

established for the purpose of monitoring the implementation of recommendations.

The Nova Scotia Advisory Commission on AIDS

The Nova Scotia Advisory Commission on AIDS (NSACA) was established in September 1989 to advise the Minister of Health on matters relating to HIV/AIDS. In late 1990, while developing its operational plan, the NSACA decided that based on the Nova Scotia experience with HIV, it was important to have a unified and strategic approach to this disease. Commission members believed that the NSACA could play a leading role in defining a Provincial AIDS Strategy for Nova Scotia. The Strategy would be built on partnerships, and have measurable objectives so that the Nova Scotia government could more effectively continue its role in preventing the spread of HIV and caring for the people affected.

The Nova Scotia Initiative

Recently, national, regional, and local governments have begun more comprehensive planning efforts in order to limit the spread of HIV Disease and reduce, if possible, the impacts of the disease, both on individuals and society. Few national governments have adopted strategies specific to HIV Disease, although notable exceptions are Australia and New Zealand. The Canadian government has been active in providing financial support to local and national AIDS service organizations, however, it has not been effective at cooperating with provincial governments in ensuring that a national strategy is implemented. At the present time, Canada has an "agenda" regarding HIV Disease, but the development of a true national strategy remains to be accomplished. In an effort to establish a well-defined strategy for Nova Scotia, the NSACA met with representatives of appropriate government departments, as well as members of local AIDS service organizations (ASO's), to determine present and future needs regarding HIV Disease, and to set priorities regarding these needs. Two working sessions were held in early 1991, followed by consultation with individual participants and organizations (for list of participants, see Appendix I). This document is the result of the deliberations of those parties and the Advisory Commission.

Our deliberations on strategic questions, followed the format of the national agenda (Health and Welfare Canada, 1990). The four major areas considered were:

-Education and Prevention

-Protection, Care, Treatment and Support of those infected with and affected by HIV.

-Research

-Coordination of effort among governments and AIDS service organizations

Within each subheading, the working group identified existing and emerging issues, and needs related to these issues. Needs were determined from the standpoint of the delivery sector which should be providing a service; the source of resources to accomplish the need; the existence of a policy framework within each delivery sector; existing government programs which are or should be answering the need, and existing community-based programs which are or should be meeting each need.

GUIDING PRINCIPLES

The objectives of the Provincial Strategy are based on the following guiding principles, which have been supported by many AIDS service organizations, provincial governments, and federal governments throughout the world, including the Canadian government (Health and Welfare Canada, 1990).

1. HIV Disease should be eradicated, and the only acceptable goal for the future is zero incidence of infections.

2. Existing programs which ensure the high quality care of individuals affected by HIV Disease must be maintained.

3. In order to achieve the goal of eradicating HIV, it will be necessary for all levels of government, AIDS service organizations, individuals living with HIV, caregivers, the health care and social services sectors, researchers and educators to work cooperatively, to effectively utilize available resources, reduce duplication of effort, and to ensure optimum integration of efforts.

4. No single effort by government, by any agency or by any individual will be sufficient to educate and provide appropriate services to all Nova Scotians with respect to HIV and AIDS. Nova Scotia is comprised of individuals from many unique cultural, religious, and social backgrounds, and our education and service delivery efforts must reflect this diversity. Every effort should be made to seek input from representatives from various ethnic and cultural backgrounds as well as from persons living with AIDS.

5. Both immediate and long-term responses are required to accomplish the objectives outlined in the strategy. Objectives have been assigned to one of three levels in recognition of this fact. Issues requiring an immediate allocation of resources to address a known need will be rated accordingly. Designation of level provides direction on how to proceed in responding to objectives rather than placing any inherent importance on each sub-area.

STRATEGIC OBJECTIVES

The populations affected by HIV Disease have changed during the past decade, as have the behaviours which encourage transmission of the HIV. Both immediate and long term objectives leading to the strategic goals have been established and are discussed in the remainder of this document. It must be borne in mind that these objectives must be reexamined on a frequent basis to ensure that provincial efforts remain directed toward the goals.

Strategic objectives have been grouped into four categories:

1. Education and Prevention
2. Protection, Care, Treatment and Support
3. Research
4. Coordination of Effort

DESIGNATION OF LEVEL

For purposes of clarification and simplicity, strategic objectives have been classified using a three level system. Assignment of level was based on the balance of three factors:

1. Perceived Need;
2. Existing Resources; and
3. Potential Benefits.

Objectives are designated as level one when:

1. the **perceived need** for the outcome of the objective is **great;**

2. **the existing resources** available to fulfil the objective are **few**; and

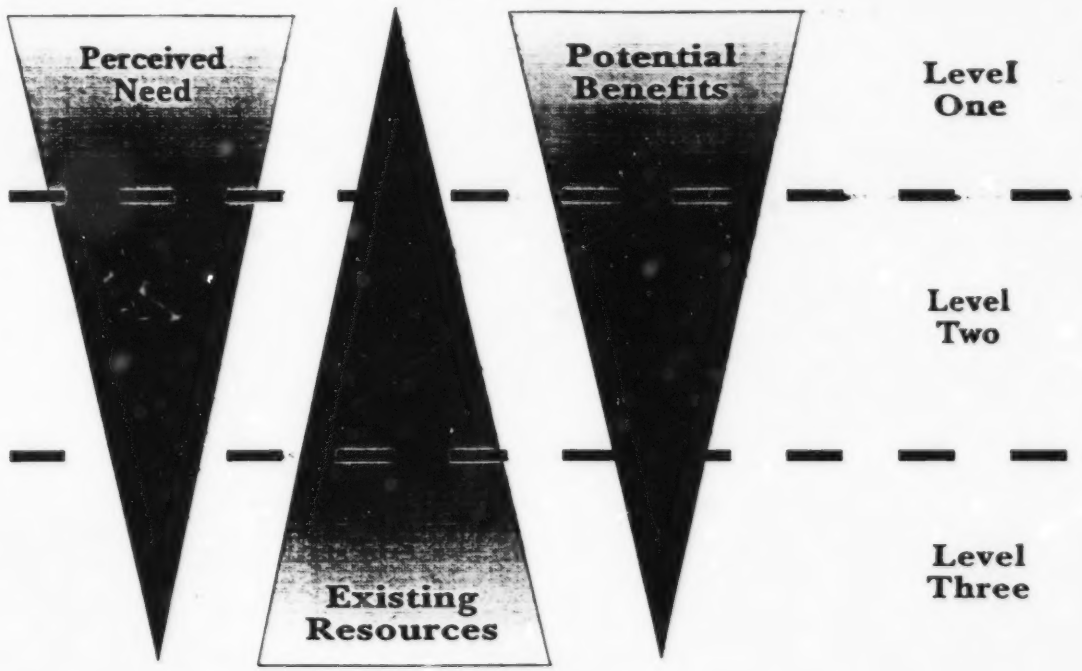
3. the **potential benefits** of the objective are **great.**

Figure 1 is a graphic representation of the relationship among Perceived Need, the Potential Benefits to be gained by meeting that need, and the extent to which Existing Resources are being applied.

Designation of level reflects the importance of emerging issues but does not mean that existing efforts can therefore be reduced. Level three objectives, in most cases, require **ongoing provision of resources**, whereas level one objectives require **immediate commitment of fiscal and human resources to allow for action.**

Because priorities change over time, the assigned levels must be continually revised based on changing perceived need and achievement of objectives.

FIGURE 1



EDUCATION AND PREVENTION

In the absence of a cure or vaccine, education remains the key element in preventing further spread of the HIV. It is apparent that although significant educational efforts have been made to provide the general public and target groups with appropriate educational materials, there remains a perception that HIV Disease is primarily a concern of the male homosexual population, and is of little concern to other societal groups. Therefore, information about the risk of HIV infection must continue to be communicated to the general public, using various methods to reach the culturally diverse populations of the province.

While public awareness campaigns are necessary to increase and maintain awareness, specifically targeted programs encouraging risk reduction behaviour are required to reach populations which may be at increased risk of infection. Establishment of targeted educational programs for three populations has been designated as a level one issue: men who have sex with men; illicit injection drug users; and young people between the ages of 13 to 18. It must be acknowledged that target groups are not homogeneous clusters of individuals – each group is comprised of individuals with vastly differing cultural, religious and social backgrounds. Different strategies developed in partnership with each target group will be required.

Level One Issues

Men Who Have Sex With Men

To date, the population most affected by HIV Disease have been men who has sex with men. Evidence from Nova Scotia and other jurisdictions suggests that behaviour modification on the part of the gay community is age specific, and that young homosexual men who are becoming sexually active are not practising sexual behaviours which will prevent transmission of the virus. There is also evidence to suggest that older men are reverting to unsafe behaviours. Therefore, new efforts must be made to reach and educate these as well as other segments of this population.

Since July, 1991, the Nova Scotia Department of Health has responded to concerns regarding AIDS education for men who have sex with men. Funds have been provided for AIDS Nova Scotia to develop prevention education programs for this population. This sponsorship will continue until July 1992.

Illicit Injection Drug Users

Illicit injection drug users (IIDU's) have shown the highest rate of increase in HIV infection during the last three years in some jurisdictions, most notably in large urban centres in the United States. Although Nova Scotia has not seen a significant number of people with HIV infection related to illicit injection drug use, the capacity for very rapid movement of the virus through this population due to needle sharing, must remain a concern. Local examples of hepatitis B transmission by this means have occurred during the last two years in Nova Scotia, highlighting the seriousness and prevalence of needle sharing behaviour in this province. It is estimated that there may be 2500 to 10,000 IIDU's in Nova Scotia.

Presently, illicit injection drug use represents the primary transmission behaviour for only one known AIDS case reported in Nova Scotia. However, because HIV infection can spread very rapidly through the injection drug using population, and from this population to the wider community through unsafe sexual behaviours and mother to fetus transmission, prevention of HIV among IIDU's demands greater attention in the coming months and years. As witnessed in other countries, there is the potential for this province to experience a shift from unsafe sex to needle sharing as the primary risk activity for exposure to HIV.

The Department of Health is presently awaiting final submissions from ASO's for a program regarding illicit injection drug use at the street level.

Young People Aged 13 - 18 Years

The Canada Youth and AIDS Study (Health and Welfare Canada, 1988) indicated that Nova Scotia youth of high school age are as sexually active, if not more sexually active, than the national average. It is therefore, critical that appropriate information be provided to high school students and other young people of that age group, which will allow them to modify their behaviours to restrict HIV transmission.

The Department of Education implemented the Personal Development and Relationships (PDR) Program in 1988. This program is offered to all Junior High School students, and contains a unit on AIDS education in each of the three years the program is offered. At the present time, however, such a program is lacking at the senior high school level, and AIDS education in grades 10 to 12 is not offered in a consistent fashion throughout Nova Scotia. There are plans to implement a compulsory Career and Life Management Course in grade 10 by the year 1996. AIDS education would be offered as one component of the course. An interim program should be implemented in Nova Scotia high schools during the 1992/93 school year, and be continued until the Career and Life Management program is fully instituted.

The NSACA has entered into discussions with the Nova Scotia Department of Education regarding the implementation of an appropriate interim program for high schools. As of this writing no commitment has been forthcoming from the Minister of Education on this topic.

Education and prevention programs must also focus on street youth, youth who interact with street youth, and young employed and unemployed single men and women who have not completed secondary school. These individuals are hard-to reach given that they are not accessible through standard institutional settings.

Multifaceted services need to be coordinated to address the vulnerability of today's youth to HIV infection. Services which have proven successful in other Canadian cities include outreach or alternative programs like crisis centres, shelters and hotline services. Traditional child welfare services are currently burdened with increasing demands for services and decreasing resources. Departments responsible for Mental Health, Community Services, Education and Recreation Departments need to coordinate planning and funding efforts, to make programming more cost effective and to provide holistic services to families. Such a model would be preventive in nature and separate from the child welfare system.

Many cities in Canada have coordinated the efforts of youth service agencies and provide innovative programming for youth and families - provincial AIDS planning and education could be best delivered through this model.

Effective education and prevention strategies must take into consideration that this group is not homogeneous. Street youth, like other peer groups, require that messages be adapted to the cultural norms by which they live. The educational needs of this group are of immediate importance and will remain an ongoing concern for the foreseeable future. Continual evaluation of new and existing programs is required to ensure that individuals at risk are receiving education in a way which is appropriate for encouraging behaviour modification on an ongoing basis.

Level Two Issues

Targeted programming for individuals whose partners practice high risk behaviours is a level two concern, as is provision of HIV/AIDS specific policies and education programs in workplace settings.

Sexual Partners of Individuals at Risk

Members of the general public who have sexual partners who are engaged in high risk activities are also themselves at increased risk of contracting HIV. They are usually unaware of their partner's unsafe behaviours and do not consider themselves to be at risk for contracting HIV, therefore they do not usually concern themselves with safer sexual and drug use practices. Both males and females

may be sexual partners of individuals practicing high risk activities.

Sex Trade Workers were among the first to educate themselves about prevention of HIV transmission between themselves and their clients. However, there is little evidence to indicate that they protect themselves equally in sexual relationships with partners who are not clients. Therefore it is important that the government ensure that educational programming is available to Sex Trade Workers which will reduce the risk of HIV infection of their non-client partners.

Educational efforts to reach these populations must be carefully considered and targeted. The type of message which will be effective may be quite different than that aimed at the general public.

Workplace Policies and Education Programs

Although most Nova Scotia school boards and universities have adopted policies relevant to HIV Disease, this is not true of businesses or correctional facilities. Given the prevalence of AIDS in the province, it is understandable that there is an unwillingness to commit resources to policy development and related employee education . It is also well known that the majority of institutions have not instituted policies regarding HIV Disease until an infected individual has become known within the institutional setting. In many instances this has caused significant disruption. Therefore, by having policies in place prior to such an event, the workplace may be able to respond in a truly sensitive and appropriate fashion, thereby limiting any possible disruption.

Level Three Issues

Level three issues include targeted programming for those populations which will be increasingly affected by HIV, people living with HIV and their caregivers, and incarcerated populations. Effective coordination and utilization of both governmental and community based educational resources which currently exist also fall within this category.

Populations Increasingly Affected by HIV

Throughout the AIDS epidemic, different target populations affected by HIV have continued to emerge, and educational efforts have been directed at these populations accordingly. It is vitally important that the Province be vigilant in identifying new populations requiring targeted educational programming, and that the objectives outlined in this Provincial Strategy document remain flexible to allow for the identification of new priorities in education and service delivery, should the need arise.

Persons Living With HIV and Their Caregivers

It is important that education strategies not only focus on preventing transmission of HIV, but also on AIDS prevention for those who are already infected with HIV, and their caregivers. Once again, it is important to recognize the diverse needs present within this target population, for it includes gay men, recipients of contaminated blood products (including hemophiliacs, individuals with bleeding disorders, and individuals who received HIV contaminated blood transfusions), women, illicit injection drug users, and many others. While many of these individuals require much of the same information (for example, information about healthy living, treatments, safer sex practices, and availability of support services), the manner in which this information is delivered must be sensitive to the diversity of the group.

Incarcerated Populations

While there are no reliable estimates for the incidence or prevalence of HIV infection in the Nova Scotia correctional system, two of the highest risk activities in the transmission of HIV (needle-sharing, and unprotected anal intercourse) are suspected to be present in higher proportions in the inmate population than in the general public. There is added risk in the provincial correctional system because of the high turnover of prisoners.

Education and prevention strategies should be developed for this population. Mandatory educational programs for inmates and workers should be provided, and a realistic assessment of

frequency of occurrence of risk behaviours within the provincial correctional system should be undertaken. Based on the results of such an assessment, prevention strategies should be developed.

Cooperation and Collaboration

Although the Province has initiated educational programs within the public school system and has encouraged universities and community colleges to provide materials relevant to AIDS, a very large proportion, perhaps most, of the burden of education has rested with community based groups.

An environment which fosters cooperation between government departments, between community groups, and between the government and community groups would ensure that educational efforts are not duplicated, and that resources are maximized.

Maintaining Public Awareness

The objectives of a public awareness campaign are to provide up-to-date HIV-related information and to sensitize the public to the issues related to HIV Disease. It is unlikely that such an awareness campaign would be an effective vehicle for encouraging behaviour change. Nonetheless there is the potential for such a campaign to foster a supportive public environment for people affected by HIV and to maintain public interest in the disease.

EDUCATION AND PREVENTION: STRATEGIC OBJECTIVES

Level One Objectives

Targeted Programming: Men Who Have Sex With Men, Illicit Injection Drug Users, and Young People: Ages 13 - 18

- The Province should continue to support the establishment of targeted educational programs for three groups:

    1. men who have sex with men;

    2. illicit injection drug users; and

    3. young people between the ages of 13 and 18 years of age, including the implementation of an appropriate AIDS educational program for high schools.

Level Two Objectives

Targeted Programming: Sexual Partners of Individuals at Risk

The Province should ensure that:

- educational programming is implemented that helps the sexual partners of people at risk negotiate safer sex with their partners .

- educational programming is available to women and men working in the sex trade industry and men who have sex with men whose partners fit these criteria.

Targeted Programming: Provision of HIV-Specific Education and Policies in Provincial Workplaces.

- The Province should adopt an AIDS policy for the Civil Service which serves as a model for other public and private institutions in the province.

Level Three Objectives

Targeted Programming: Populations Increasingly Affected by HIV, Persons Living With HIV and their Caregivers, and Incarcerated Populations

- The Province should support the establishment of targeted educational programs for three groups:

    1. populations that will become increasingly affected by HIV;
    2. persons living with HIV and their caregivers; and
    3. incarcerated populations.

Government Leadership in Coordinating Provincial Education and Prevention Programs

The Province should:

- implement a mechanism whereby government can act to coordinate the valuable experience existing in community groups with existing public educational facilities in order to share this information as widely as possible without creating undue stress on community organizations.
- institute a regular program of inservice education utilizing community based agencies for their expertise for training AIDS/Sexuality educators and should encourage educators and school boards to disseminate this information as widely as possible.

Maintaining and Increasing Public Awareness

The Province should develop, implement, and evaluate a provincial public awareness campaign on HIV Disease that would:

- emphasize the risk to the general population through province-wide information campaigns;
- emphasize that denial of risk by many groups in society is based on the perception that a single group is more at risk, rather than a rational assessment of their own behaviours such as sexual activity or needle sharing.
- foster a supportive public environment for those affected by HIV disease.

PROTECTION, CARE, TREATMENT AND SUPPORT

Level One Issues

HIV Testing and Reporting Methods

To date, the Provincial Government has required that all positive HIV antibody test results be reported to the appropriate authorities, along with the name of the individual who has tested positive. However, there is a perception on the part of many individuals who may be most at risk that the reporting of an individual's name could lead to significant abuses, and that there is potential for an individual who has tested HIV positive to be adversely affected in terms of employment, housing, or in relationships with friends and family. These fears mean a certain number of those individuals who might be most at risk have avoided HIV testing, and therefore are not aware of their own HIV status.

Because individuals who are HIV positive can gain significant health benefits through early diagnosis and health education (pre-test and post-test counselling), it is important that a reporting procedure be implemented which will encourage the largest number of individuals to be tested as soon as possible.

AIDS often has affected individuals who are marginalized by society. Fear of exposure of an individual's sexual orientation or drug behaviour has been and continues to be a very real concern in both social and legal contexts.

A non-nominal reporting system and efforts to build trust in affected populations would encourage more people to be tested, and help to ensure the confidentiality of their HIV status.

Level Two Issues

Human Rights Act Amendments

It is important that consideration be given to education for the public regarding the recent amendments to the Human Rights Act providing for protection from discrimination based on sexual orientation and an irrational fear of disease. Educational efforts are required so that affected populations are aware of the protection afforded them and the general public becomes aware of the ramifications of discriminatory actions.

Also, the current resources of the Human Rights Commission should be examined to ensure that the Commission has appropriate human resources to respond to formal complaints arising as a result of the amendments to the act. If the resources of the Human Rights Commission are not sufficient, the complaint process will only increase in duration therefore acting as a deterrent to the affirmation of legal rights.

Availability of Anonymous Testing

Concerns have been raised regarding the willingness of many individuals (most of whom are possibly most at risk) to undergo testing due to concerns about loss of confidentiality, and the effects of a positive test result on their personal lives. An anonymous testing site would allow these individuals to determine their HIV status without concern for their personal medical information being susceptible to a breach of confidentiality.

Implementation of anonymous testing would require that a mechanism be developed for informing those who may be at risk from individuals who receive positive tests under an anonymous testing system. The assumption of self-reporting and informing on the part of HIV positive individuals is open to interpretation, and may not be a valid consideration in this instance.

Education for Health Professionals

Due to the low prevalence of HIV Disease in the province, most health professionals have not encountered an individual who is HIV positive, nor have they received appropriate pre-service or in-service education regarding HIV disease or skills in HIV counseling. Many health care

workers, however, have encountered individuals who are concerned that they have placed themselves at risk for HIV and may be HIV infected.

Financial Support to AIDS Service Organizations

ASO's have received most of their funding from the federal government and limited support from private donations. The Provincial Government has primary responsibility for health care and promotion and has been enthusiastic about the response of ASO's to the AIDS epidemic, although it has not provided long-term financial support to existing organizations. If federal contributions are reduced and private donations do not increase, there will be a need for increased provincial support.

Level Three Issues

Access to and Availability of Treatment

The provincial government has ensured that hospitals have adequate resources so that persons with HIV-related illnesses are able to receive appropriate in-patient and out patient care, and has also made anti-HIV drugs available free-of charge. It is important that this high standard of treatment be maintained. It is also important that other options for treatment be explored and made available if appropriate, such as various complementary therapies.

Access to and Availability of Care

The Province of Nova Scotia has committed itself to providing equal care to individuals across the province. The ability of regional institutions to cope with persons with HIV Disease depends to a large extent on peer education, support and counselling for care providers as well as care recipients. It is a well known fact that care providers tend to react negatively to their first exposure to individuals with HIV Disease but rapidly lose their fears once they have gained experience with the disease.

Large Canadian urban centres with a high prevalence of AIDS, such as Toronto and Vancouver have found it appropriate to establish hospices for the care of terminally ill AIDS patients. While the numbers of persons with AIDS in Nova Scotia to date have not justified the establishment of such a facility, such a need may arise in the future.

Access to and Availability of Social Services

People with HIV Disease often have unusual requirements for social services and supplementary medical and/or nutritional needs. HIV Disease is unusual in that individuals fluctuate between critical illness and the capability of returning to a very active life shortly thereafter, a cycle which is repeated, sometimes for several years. Because of this relatively unusual disease course many individuals have recurrent "catastrophic" needs because they do not qualify for social assistance at their time of greatest need and may become economically and physically impoverished over a short period of time.

PROTECTION, CARE, TREATMENT AND SUPPORT: STRATEGIC OBJECTIVES

Level One Objectives

HIV Testing and Reporting Methods

- The Province should implement a non-nominal testing/reporting procedure which would not require the use of information which could identify an individual to others.

Building Trust in Affected Populations

- The Province should continue to build linkages with the populations which have been and are likely to be affected by AIDS and to demonstrate that abuses of confidentiality and human rights, as supported by the Human Rights Act, will be dealt with in a rapid and sensitive manner.

Level Two Objectives

Amendments to the Human Rights Act – Education and Resources

- The Province should conduct educational programs to make affected populations and society at large aware of the recent changes to the Act and the ramifications of discriminatory actions.

- The Province should ensure that there are sufficient resources for the Human Rights Commission to respond to formal complaints in a timely and sensitive fashion.

Ongoing Consideration of Anonymous HIV Antibody Testing and Associated Counselling

- The provincial government should continue to give consideration to the establishment of an anonymous testing site.

Ongoing Provision and Development of Undergraduate, Post-Graduate and Continuing HIV/AIDS Education for Health Professionals

- The Province should encourage on-going HIV/AIDS education and curriculum development for health care professionals, regarding counselling and working with individuals with HIV Disease.

Financial Support for AIDS Service Organizations

- The Province should consider its funding strategies in terms of core funding and long-term project funding for ASO's as part of the overall strategy for responding to AIDS.

Level Three Objectives

Access to and Availability of Treatment

The Province should:

- maintain its high quality of treatment for people with HIV Disease by assuring that appropriate drugs continue to be made available free of charge through provincial institutions.
- assure that high quality care is available in regional hospitals.
- review the availability of complementary therapies such as nutritional supplements on a consistent basis.
- ensure that physicians are aware of the need for counselling and patient consent with regard to proposed treatments.

Access to and Availability of Care

The Province should:

- ensure that out-patient care for people with HIV Disease in most regional hospitals is upgraded.
- continue its efforts in providing care for persons with HIV Disease in, or as close to, their home as possible and should ensure that the integrated hospital, community and home care network is functional on a province wide basis.
- ensure that persons with AIDS continue to be cared for in a sensitive and compassionate manner.
- consider the possibility of establishing an AIDS hospice

Availability of Social Services

- The Province should examine ways in which it can more equitably provide service to individuals with recurrent short term "catastrophic" needs in order that their health status not be compromised.

RESEARCH

Objectives related to research have all been assigned to level three because Nova Scotian researchers have historically cooperated with others in their field both nationally and internationally. There may be specific areas in which research on HIV Disease in Nova Scotia would provide information not available from other sources. The research objectives include encouragement of cooperative biomedical research; epidemiological research; examination of social-behavioural patterns; and economic and legal ramifications.

Biomedical Research

In Nova Scotia the number of individuals with AIDS has been small. Although Nova Scotians with HIV Disease have participated in national and local research programs, their involvement in biomedical research is constrained by virtue of their small numbers. Consequently, local researchers also are limited as investigators in national and international studies.

It is important that the province encourages local researchers to participate in national research programs, and ensures that opportunities to conduct biomedical research in Nova Scotia are not overlooked.

Complementary therapies to treat HIV infection are becoming increasingly popular, however, there is little information available about the efficacy of such treatments. Whenever possible, researchers should be encouraged to investigate complementary therapies as well as more standard therapies.

Epidemiological Research

Epidemiological research is important in order to allow for adequate planning in both the medical and social service sectors, as well as to examine risk factors and behaviours which may be particular to the Nova Scotia context. At present, there is sufficient epidemiological data to present an accurate picture of AIDS in Nova Scotia, but the same cannot be said for HIV infection. Funding is available from the Federal Government to conduct local seroprevalence research provided that those research proposals which are accepted are endorsed by the provincial Department of Health. The Province should continue to endorse seroprevalence research, so that a true indication of the incidence and prevalence of HIV in Nova Scotia can be obtained.

Social Behavioral Research

Only through regular monitoring of behaviour change and educational levels, will the Province be able to determine the success of education and prevention programs, as well as identify populations where new or revised education strategies are required. Whenever national social behavioural research programs provide an opportunity for local involvement, the province should encourage and support the participation of local organizations and individual researchers.

In some cases, specific provincial initiatives may be required to evaluate behaviour change in culturally unique communities within Nova Scotia. The province could provide encouragement and support to local ASO's who may be endeavouring to undertake such research.

Economic/Legal Research

While persons living with HIV (PLWHIV) in financial need and unable to obtain or maintain employment due to their medical condition are able to access social service programs, some HIV positive persons have special needs which are not met through social service programs. It is important that the province monitor the economic needs of PLWHIV, to identify gaps in service and work toward elimination of such gaps.

The legal ramifications of HIV Disease are diverse and complex. The province should encourage research that will assist in the development of fair public health policies with respect to HIV infection. Also, implementation of the amendment to the Human Rights Act which precludes discrimination

based on irrational fear of disease should be monitored, to ensure that discriminatory practices against people living with HIV are dealt with expediently, and in accordance with the law.

Collaboration Among Researchers

The provincial government must play an important role in encouraging the continuation of ongoing research and initiation of new research projects, as well as promoting collaboration among researchers.

RESEARCH : STRATEGIC OBJECTIVES

Level Three Objectives

Social Behavioural Research

The Province should:

- take a stronger role in assuring more social behavioral research is undertaken in Nova Scotia.

- continue to monitor changes in education levels and changes in behaviour in order to evaluate the success of educational campaigns at regular intervals on an on-going basis.

Epidemiological Research

- The Province should continue the collection of epidemiological data on individuals who are HIV^+.

Economic/Legal Research

The Province should encourage:

- ongoing evaluation to determine the extent to which the economic needs of people living with HIV/AIDS are being met, and to identify gaps in service.

- ongoing examination of the legal ramifications of HIV/AIDS especially from public health and human rights perspectives.

Biomedical Research

- Where direct funding is available from national research funding agencies, the provincial government might show encouragement and support for biomedical research by assisting in the provision of a research infrastructure, (i.e. research facilities and assistants) to local researchers.

- Researchers in Nova Scotia should continue to be involved in national research programs.

- In addition to research on standard therapies, research on complimentary therapies should be encouraged.

- The Province should examine the existing AIDS research network to determine if in fact research opportunities are being fully exploited at the local level. Assessment should occur at regular intervals as a means of monitoring research progress.

Promote Collaboration Among Researchers

- The Province should encourage the ongoing validation and evaluation of projects and programs initiated under its aegis.

COORDINATION OF EFFORT

The primary responses of the Government of Nova Scotia to the challenge of HIV Disease have been education in provincial educational institutions, and the provision of health care. The primary response of the community has been to provide education to the general public, counselling and financial support to those affected by HIV Disease, and educational support to provincial institutions. In some cases government departments have not coordinated their efforts. In many cases government and community groups have not communicated, much less coordinated their efforts. This has led to inconsistent access to services for persons with HIV Disease and duplication of educational programs. It is important that both the government and the community understand and appreciate the role which each is best equipped to play in accomplishing the strategic objectives. The input of many individuals, communities, agencies and levels of government is required to respond effectively to the complex issues of HIV Disease. Collaboration between governments and communities, between various levels of government and between provincial government departments is essential to ensure efficient use of limited resources. One of the keys to developing a comprehensive approach to HIV/AIDS education, care and research is the building and nurturing of networks that include all of the partners in the response to AIDS.

Level One Issues

Consistent and Equal Access to Social Services

In the metro area alone, it is estimated that 25 individuals with HIV disease require access to the social services network due to the fact that they are unable to maintain their employment consistently throughout the course of their illness. The social services system in Nova Scotia does not easily accommodate individuals whose disease status changes so radically in a short period of time, nor is it consistent between provincial and municipal agencies or between municipalities. While this problem is not limited to AIDS, this disease has highlighted the problem province-wide. Standardization is required.

Level Two Issues

Coordination of Health Promotion and Care

The Province has a primary responsibility for health care and a commitment to health promotion. Coordination is required so that persons with HIV throughout the province have equal access to health care and social services. Also, all efforts to educate Nova Scotians about HIV and AIDS need to be carefully coordinated to avoid misuse of resources. This will involve coordination between government departments, between various levels of government, between community groups, and between government and the community.

Level Three Issues

Coordination of Programs

The need to provide medical and social services to individuals with HIV Disease has highlighted the requirement for better communication and coordination among Provincial Government departments and between the Provincial Government and the municipalities. As discussed elsewhere in this document, individuals with HIV Disease face recurring and rapid changes in health status which may require them to access services from a variety of sources over a short period of time. An individual may require critical hospital care followed by the need for coordinated home care and social assistance, and this sequence may be interspersed with periods of good health during which regular activities can be maintained. It is important that both levels of government work toward better coordination of services for individuals with recurring needs. Within the Provincial Government, it is important that programs be coordinated to ensure the well being of persons with HIV.

COORDINATION OF EFFORT: STRATEGIC OBJECTIVES

Level One Objectives

Consistent and Equal Access to Social Services

- The Provincial Government through the Departments of Community Services and Municipal Affairs and the municipalities should examine access to the social services network for the purpose of standardizing the provision of social services province-wide.

Level Two Objectives

Coordination of Health Promotion and Care

The Province should:

- play a central role in the coordination of health promotion programs aimed at increasing the awareness of target audiences and the general public.

- assure that all Nova Scotians receive adequate protection from HIV Disease by:

    1. Actively working with the Federal government and the other provinces and territories to provide educational materials which are appropriate for recognized target groups. Wherever possible, these governments should work together to produce and disseminate materials which are appropriate nationwide.

    2. Helping to coordinate the activities of community based organizations to ensure that little overlap of high quality services occurs and that appropriate NGO's are encouraged to develop programs to reduce the spread of disease.

Level Three Objectives

- The Province should establish a mechanism whereby the Departments of Health, Community Services, and Municipal Affairs regularly consider ways in which they can better provide services to people with HIV Disease in a coordinated and sensitive fashion.

IMPLEMENTATION AND EVALUATION

Implementation

The objectives of the Provincial Strategy provide direction and focus for the attention of the Nova Scotia government, about important and timely HIV/AIDS issues. In order to assure that the strategic objectives are implemented according to the priority rating system of the Provincial Strategy, an implementation plan is required.

The Province should appoint an interdepartmental committee mandated to oversee the implementation of the Provincial Strategy on AIDS, under the auspices of the NSACA. The Interdepartmental Committee should be chaired by the Chairperson of the NSACA, which will act as the secretariat to the Committee.

The Ministers responsible for Health, Community Services, Education, Municipal Affairs, Housing, the Solicitor General, the Human Rights Commission, the Civil Service Commission, and the Women's Directorate will appoint individuals from within their respective departments who will be appropriate members of the Committee. The Nova Scotia Government Employees and Teachers Unions should also be represented. Members of the Committee should have knowledge about and commitment to the issues, of HIV Disease and have responsibility for programming related to those issues within their agencies.

The Interdepartmental AIDS/HIV Committee will meet twice each year, and at other times as required and will report to government annually.

Evaluation

Evaluation must be considered an integral component of all plans for implementation of the strategic objectives. The objectives are intended to be measurable, in order to facilitate the evaluation process. Evaluation of implementation progress will require input from various representatives from the government and community. A practical mechanism must be utilized so that input from all partners can be received on a regular basis. To be most effective, the evaluation process should be undertaken concurrently with the implementation phase of the strategy. The NSACA could play a critical role in facilitating this evaluation.

GLOSSARY

AIDS (Acquired Immune Deficiency Syndrome): A disease believed to be caused by a virus known as HIV, in which the body's immune system is seriously damaged, leaving it vulnerable to infections and some rare cancers that ultimately result in death.

Anti-HIV Drugs: Substances which interfere directly with the life cycle of HIV.

ASO's: AIDS Service Organizations

Complementary therapy: Non-traditional treatments used in addition to traditional medical therapy, usually self-prescribed.

HIV (Human Immunodeficiency Virus): the virus that is believed to cause AIDS.

HIV test: A group of laboratory tests whose purpose is to detect and confirm the presence of antibodies to HIV. It is used on all donated blood and organs and in all clinical testing programs. It is also used at alternative or anonymous testing sites. If antibodies are detected, it is assumed that the individual or organ is infected.

HIV Disease: In this document, refers to the spectrum from infection to expression of full blown AIDS.

Homophobia: The unreasonable hatred or fear of homosexuals or homosexuality.

Incidence: The rate at which a certain event occurs, as the number of new cases of a specific disease occurring during a certain period.

NGO: Non-governmental organization.

Opportunistic Infections: The diseases which are caused by agents that are frequently present in our bodies or environment but which cause disease only when there is an alteration from normal healthy conditions - for instance, when the immune system becomes weak or damaged.

PDR program: Personal Development and Relationships program, implemented by the Department of Education in 1988. This program is offered to all Junior High School students, and contains a unit on AIDS education in each of the three years the program is offered.

Prevalence: the total number of cases of a specific disease in existence in a given population at a certain time.

Street Youth: Young people who live or spend a great deal of time on the street, who do not live at home or regularly attend school.

Vaccine: A preparation of killed or living attenuated organisms or part of micro-organisms which can be administered to produce or increase immunity to a particular disease.

Viruses: Submicroscopic pathogens that grow and reproduce only inside living cells, thus causing disease.

BIBLIOGRAPHY

Federal Centre for AIDS. (1991). Surveillance Update: AIDS in Canada, 10, 0, 1-5.

Health and Welfare Canada. (1991). Canada Diseases Weekly Report, 17(27), 137.

Health and Welfare Canada. (1990). HIV and AIDS: Canada's blueprint. Ottawa, ON.

Nova Scotia Advisory Commission on AIDS. (1991). AIDS education in Nova Scotia Schools. Halifax, NS.

Nova Scotia Task Force on AIDS. (1988). The challenge of AIDS: A Nova Scotian response. Halifax, NS.

Veniot, P. (1991). HIV/AIDS in the Provincial Correctional System: A Discussion Paper. (Available from Nova Scotia Advisory Commission on AIDS)

APPENDIX 1

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